Barriers and Facilitators to Adherence to Follow-up for Abnormal Cervical Cytology: A Review of the Evidence with Implications for Clinical Practice

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Abstract

Cervical cancer is one of the most preventable cancers because of its slow progression, cytologically identifiable precursors and effective treatments (Leyden et al., 2005). However, it remains the third most common gynecological cancer, leading to an unnecessary number of deaths annually (Brookfield, Cheung, Lucci, Fleming & Koniaris, 2009). The key to decreasing the incidence of cervical cancer deaths begins with screening Pap smears and adherence with recommended follow-up care for abnormal results. Transportation, childcare issues, financial constraints, and need for reminders are consistently recognized as barriers to follow-up care (Abercrombie, 2001). Transportation and financial incentives, reminders, patient educational materials, and case management are effective facilitators to follow-up (Engelstad et al., 2005). Despite an automated reminder call system and transportation incentives being available at Muskingum Valley Health Centers (MVHC), the number of patients who do not return for follow-up appointments remains high.

The purpose of this evidence-based practice (EBP) project was to ascertain common barriers and facilitators that either prevent or help patients make return visits and interventions that could increase adherence for return visits. To that end, this EBP project includes a thorough review and synthesis of the literature and a survey of the patients seeking care in the gynecology service line at Muskingum Valley Health Centers to understand their perspective about barriers and facilitators to plan for future interventions at the center.

An extensive literature review was conducted utilizing several different data bases in order to find the highest level of evidence. During this process, the search methods were validated by a Health Sciences Librarian who is has experience in EBP. After obtaining the literature, it was analyzed and compared to the information obtained from the questionnaires from MVHC. The evidence was then used to determine the barriers and facilitators to follow-up care for the patients at MVHC. Based on the evidence and findings, amendable changes were determined.

Introduction and Background

Cervical cancer is one of the most preventable cancers because of its slow progression, cytologically identifiable precursors and effective treatments (Leyden et al., 2005). Yet, it remains the third most common gynecological malignancy diagnosed in the United States (Brookfield et al., 2009) with an estimated 3644 preventable cervical cancer deaths each year (Sabatino et al., 2008). When diagnosed early, the likelihood of survival is close to 100% (Eggelston, Coker, Das, Cordray & Luchok, 2007). A key reason for the high number of deaths caused by this preventable cancer is failure to obtain follow-up care after an abnormal screening with the Pap smear. The rates of loss to follow-up for abnormal Pap smears have been found to range from 30% to 50% (Hunt, de Voogd, Soucy, & Longworth, 2002). There are multiple factors associated with adherence to follow-up recommendations, including both demographic and psychosocial patient factors as well as healthcare system influences. (Eggelston et al., 2007).

Demographic barriers include younger or older age, nonwhite race, and lower educational level. Financial barriers include lack of insurance or ability to pay for care. Psychological issues include fear and beliefs about health and cancer. Finally, accessibility to care is demonstrated by individuals not having the time to attend multiple appointments, transportation issues and lack of childcare. In summary, there are multiple barriers to returning for necessary follow-up care. It is important to focus on barriers that are amenable to intervention; therefore, a literature search on the best evidence for intervention is needed.

The purpose of this EBP project was to ascertain the best evidence on ways to increase adherence to follow-up care recommendations and develop an intervention plan for Muskingum Valley Health Centers (MVHC). Utilizing Melnyk and Finout-Overholt's (2011) EBP approach, the following steps were performed to meet this goal:

Step 0: Cultivate a spirit of inquiry

Step 1: Develop a PICOT question

Step 2: Search for the best evidence

Step 3: Critically appraise the evidence

Step 4: Integrate the evidence with patient's values and understanding of the barriers

EBP Steps 0 – 4

Step 0: Cultivate a Spirit of Inquiry

Muskingum Valley Health Centers is a federally qualified health center (FQHC) whose mission is to provide high quality, affordable health care services to medically underserved populations regardless of their ability to pay. Women's preventative health care including annual Pap smears is provided by a variety of health care providers within the health center. Loss to follow-up care has been recognized as a potentially life-threatening consequence for women within this health center. Despite the fact that there are some interventions in place such as an automated telephone reminder system and in some cases transportation vouchers, the number of patients with abnormal Pap smears who do not follow-up in a timely manner or do not follow-up at all remains high. This prompted the author to want to obtain evidence that would assist in determining what interventions would help these women keep their follow-up appointments and could be used to develop a plan for MVHC.

Step 1: PICOT Question

A PICOT question (P=Patient population, I=Issue of interest, C= Comparison group, O=Outcome, and T=Timing) was developed to guide the literature search and the development of the patient and staff questionnaires. For this project, there was not a comparison group. The PICOT question was "In women receiving gynecological care (P), what interventions (I) will reduce barriers and facilitate adherence to follow-up (O) after abnormal cervical cytology (T)?"

Step 2: Search for the Best Evidence

Using the databases PubMed, CINAHL and Cochrane, a search for articles published from 1990-2011 was conducted to determine barriers and facilitators to abnormal Pap smear follow-up. The keywords used from the PICOT question in the search process were: barriers, facilitators, adherence, Pap smear and follow-up. The search was limited to the English language. This search yielded a total of 24 articles adding to the body of evidence related to barriers and facilitators to adherence to follow

recommendations for abnormal Pap smears. The search methods were validated by a Health Sciences Librarian who has expertise in EBP.

Step 3: Presentation and Critical Appraisal of the Evidence

The 24 articles found in the literature search are presented in *Appendix A*. The following aspects of each piece of evidence were examined in the critical appraisal process: validity, reliability and applicability. The evidence was graded using Melnyk & Fineout-Overholt's (2011; p.12) levels. A hierarchy of evidence provides guidance about the types of evidence. The hierarchy of evidence ranks quantitative research designs (i.e. systematic review of randomized control trials) as providing higher levels of confidence that the studies will have reliable answers to the study question than designs with lower levels of confidence (i.e. descriptive designs) (Melnyk & Fineout-Overholt, 2011). Level 1 is the highest level of evidence and each numerical level after it represents a lower level of evidence. Of the 24 articles: five were level one, seven were level two, one was level three, four were level four, one was level five, and six were level six. For this project, Levels 1 – 3 (13 studies of the original 24) were used to ascertain the best interventions to increase adherence because these were studies that focused on interventions.

Intervention studies.

Of the articles that are intervention studies, five were systematic reviews or meta-analysis. The systematic reviews yielded results of studies related to barriers to follow-up care and improving adherence to follow-up care after an abnormal Pap smear during a span from 1966-2001. The reviews included both randomized and non-randomized control intervention studies as well as qualitative studies. Most studies identifying barriers concluded that those at highest risk for non-adherence were minority women, women with less than a high school education, low socioeconomic status, younger than age 30 years. Additional barriers included women's limited understanding of Pap smear results, fears associated with abnormal Pap smear results, and lack of insurance, childcare and transportation. Other barriers found to affect adherence include forgetting the follow-up appointment, and administrative problems such as incorrect patient addresses and phone numbers.

The five systematic reviews indicate that effective strategies to improve patient adherence to follow-up recommendations include: (a) structured educational/counseling phone calls, (b) transportation and financial incentives, (c) office-based reminder calls and letters, (d) educational brochures and handouts regarding abnormal Pap smears, (e) slide-taped presentations, (f) and case management tracking.

Seven randomized control studies and one quasi-experimental intervention study was reviewed. One study was conducted using patients from 12 different primary health care clinics. Seven studies were conducted in various units of a hospital or medical center, all of which were located in the United States. The majority of the intervention studies used sample populations predominantly including minority women of African American (ranging from 13%-86% of the total number of participants) or Hispanic descent (ranging from 17% to 80.6% of the total number of participants). Those that were Caucasian in the studies ranged from 6%-24% of the total number of participants representing a much smaller portion of the total. The larger proportion of participants was uninsured or relied on public assistance for medical expenses. The participants were relatively young in age with most under age 35 years. One intervention study used a sample of predominately white women with an average age of 31 years, well educated, and in the middle and upper social classes. Sample sizes for all the intervention studies ranged from 108 to 4,488 participants. Intervention study times ranged from 6 months to 3 ½ years following abnormal Pap smears.

Results from the studies revealed that single or a combination of interventions is effective in improving patient adherence rates. Two studies found that telephone counseling is more effective than standard care for improving adherence to follow-up (Miller et al., 1997; Yabroff, Kerner, & Mandelblatt, 2000). Two studies describe the effectiveness of a computerized tracking system (Engelstad et al., 2001; Engelstad et al., 2005). In a study involving a combination of interventions including a personalized follow-up letter and educational pamphlet and a slide taped program describing Pap smears and the importance of follow-up compared to transportation incentives alone, transportation incentives were found to be the most effective at improving adherence rates (Marcus et al, 1992). A second study that

involved transportation incentives along with two other interventions found similar rates of receipt of follow-up care but did not find strong evidence for intervention effects (Marcus et al, 1998). Interventions supported in other studies which have been shown to improve adherence to follow-up care are: (a) educational pamphlets, (b) notification letters, (c) financial incentives, (d) telephone reminders, (e) and slide-taped education.

Limitations of the studies include a lack of consensus on the definition of "adherence". Some studies refer to adherence as a patient who completed all recommended follow-up appointments. Others defined adherence as a patient that presented for at least one follow-up appointment. Another limitation to the studies is that all but one of the studies used a sample of predominately minority women of African American or Asian descent which may limit the generalizability to white women. Although each intervention study had limitations, all documented some improvement in adherence to follow-up with intervention. In addition, each study provides and supports the development of future interventions.

Qualitative studies.

The purpose of the single qualitative meta-analysis was to determine the effectiveness of interventions designed to improve follow-up after abnormal Pap smear. The criteria for the analysis included: randomized or concurrently controlled study design, defined outcomes, and data available for abstraction. Interventions were classified as behavioral, cognitive, sociologic, or combined strategies. Twenty-two interventions in ten studies were reviewed. The most effective cognitive intervention included telephone counseling, improving adherence by 24-31%. Behavioral interventions such as patient reminders increase adherence by 18%. Video-taped peer discussions were found to be the only sociologic intervention and were not found to be associated with an improvement in follow-up. There were eight distinct interventions in three studies that used a combination of strategies. Most of the behavioral and cognitive combinations yielded an improvement in compliance by 7-13%. Varying effectiveness was found in the behavioral and sociologic or the behavioral, sociologic and cognitive combinations.

Limitations of the studies included a varying definition of abnormal Pap smear, follow-up outcome measurement and time frame used to assess follow-up. Variability in the patient populations studied could also have an effect on the interpretation of the results.

The samples of the remaining 11 studies were varied. The sample sizes ranged from 40-1216 participants. In the studies, most participants were under age 35, had completed high school, and were uninsured or covered by public assistance. The majority of studies obtained information from women of racial or ethnic minorities. The literature indicates that facilitators to follow-up care include reminders, transportation and financial incentives, and educational materials help to facilitate adherence to follow-up recommendations

Step 4: Integration of Evidence

It is unknown whether the things that prevent and help patients adhere to recommendations after an abnormal Pap smear at MVHC are similar to those found in the literature. To assess this, patient and staff data was obtained to ascertain what barriers and facilitators were present in obtaining follow-up care.

Project Procedure

After obtaining approval from The Ohio State University Institutional Review Board, packets were distributed to patients presenting to the gynecological service line at MVHC who met inclusion criteria. Inclusion criteria included: the participant was at least 18 years of age, was a patient in the gynecological service line at Muskingum Valley health Center, and was able to read and write. Exclusion criteria included the patient who was under age 18 years, failed to consent, and/or could not read and write. The packets were distributed by trained staff members. The packet consisted of a copy of the informed consent accompanied with a cover letter explaining the purpose of the questionnaire, the questionnaire and an envelope. The participant completed the questionnaire in the exam room while waiting to be seen by the provider. After completing the questionnaire, it was placed into the enclosed envelope and sealed by the participant. Following the participant's office visit, the sealed envelope was collected by a staff member and placed into a designated box in a locked drawer in the investigator's desk.

Staff members providing care to patients in the gynecology service line were provided with a packet. Their packet consisted of a cover letter explaining the purpose of the questionnaire, an informed consent, the questionnaire and an envelope marked with staff. Staff who consented to participate completed the questionnaire and then placed into the envelope. They were instructed to seal the envelope. The envelope was returned to the investigator who placed it into the box designated box, locked in the investigator's desk.

Questionnaires

The patient questionnaires (see *Appendix B*) were formatted in a check box format for quick, easy responses as well as open-ended questions that allowed the participant to provide more expressive answers. The patient questionnaire included demographic information including age, education level, income, work status, marital status, number of children and insurance coverage. There were questions which helped determine the patient's history of abnormal Pap smears, education received regarding their abnormal Pap and information about scheduling.

Staff questionnaires (see *Appendix C)* were used to obtain data about their perceptions of patient's responses to follow-up care, perceptions of patient knowledge of the Pap smear results, perceptions of the patient's own health and perception of the patient's ease of accessibility to care. These were written as open-ended questions. There was one check-box question which asked for the staff member to identify their role as a staff member.

Data Analysis

Descriptive data analysis was used to analyze closed-ended questions. Open ended responses were analyzed using McLaughlin and Marascuilo's (1990) three-phase content analysis technique. The first phase of the content analysis was to identify individual units of analysis, (i.e. a thought or a theme that appeared in the response). Each thought or theme was bracketed on copies of raw, de-identified data,

independently by two trained coders. Units of analysis were compared between members, and an interrater reliability (IRR) percent agreement was calculated using the following formula: IRR = (N_A – N_8)/Total where N_A = number of agreements, N_8 = number of disagreements, and the Total = the total number of bracketed thoughts/themes. The investigators determined that an adequate IRR is 0.90 agreement. If there was disagreement on any unit, it was discussed until a consensus was reached. All units coded were > 98% prior to discussion. The second phase of the content analysis required a coder to create mutually exclusive and exhaustive categories that incorporated all of the thoughts or themes (i.e. units), then develop names and definitions for each category. In the third phase of the content analysis, another coder sorted the units of analysis into these categories based the definitions provided by the coder in phase 2 (McLaughlin & Marascuilo, 1990). A priori level of 90% agreement was determined as acceptable for interrater reliability. For the third phase, all units were > 90% prior to discussion. Frequencies and percentages for each category were calculated.

Results

Results of Patient Surveys

Fifty women completed the questionnaires. Demographic information for the patients is included in Table D1 and D2 of Appendix D. The women ranged in age from 18 to 66 years-old (*M* = 35; *SD* = 11.54). One participant was excluded because she did not meet inclusion criteria, making the final total 49. All participants reported that their primary language was English. The majority was Caucasian (79.6%), single/divorced /separated (63.3%), insured by public assistance or without insurance (81.6%), and had completed at least nine to twelve years of education (98 %). Sixty-five percent of the participants reported that they presented for a Pap smear. Of the participants, 42.9% had received their last Pap smear one year ago. Approximately 43% percent indicated that they have had an abnormal Pap smear in the past and 40.8% of these patients followed up for an abnormal Pap smear.

Patient reasons that prevent them from returning for follow-up visits included transportation issues/distance to travel (15.0%), negative experiences (13.8%), and financial barriers (13.8%). Patients reported that having a positive experience (23.1%), motivation by health (i.e. patient is not sick, is in good

health) (13.5%), financial assistance (11.5%), and flexible scheduling (11.5%) would help them keep their follow-up appointments (see *Appendix E*).

Results of Staff Surveys

There were a total of seven staff members that completed questionnaires; three physicians, three nurse practitioners/physician assistants, and one social worker. Staff results (see *Appendix F*) revealed that 26.1% believed that transportation was a reason that prevents patients from returning for follow-up appointments. The next most frequently reported reason was health literacy issues (17.4%) and the third most commonly reported reason was financial barriers. The three most commonly reported responses from staff for things that could help patients keep their appointments were transportation assistance (25.0%), reminders (20.0%), and improving health literacy (15.0%)

Discussion

The women from MVHC who participated in this EBP project had similar demographic characteristics as those in the literature (Eggleston, Coker, Luchok, & Meyer, 2007; Engelstad, et al., 2001; Marcus et al., 1992; Miller, et al., 1997). These similarities make the information obtained both from the questionnaires and the literature search important for developing interventions for improving adherence to follow-up. The average age of the participants was mid-thirties. Most of them had completed high school and were unemployed or employed part-time. The majority of the participants were uninsured or insured by public assistance. Many were single, divorced or separated and had at least one child.

There were also some differences between the sample from MVHC and the published literature with the biggest difference being race. Most of the evidence from the literature is based on samples of predominately African American or Hispanic women (Engelstad, et al., 2001; Engelstad, et al., 2005; Miller, et al., 1997). The majority of the women from MVHC were Caucasian. It is possible that this could have influenced their responses to the questions and therefore would have an effect on determining the most appropriate interventions for these women.

Commonly reported MVHC patient responses that prevented them from returning for follow-up care were transportation and finances. Similar barriers were found in the literature. Patients at MVHC reported that having a negative experience which was defined in the categories as bad or negative experiences with staff, conditions of the clinic (i.e. cleanliness,) or care (i.e. perceptions of technique) is also an important reason for not returning for follow-up care. This is unique to this sample and was not found to be a dominant barrier in the literature. It is interesting that the study revealed that only two participants reported that forgetting the appointment was a reason for not returning for follow-up but the literature supports that reminders significantly increased the rate of follow-up care. Patients at MVHC believe having a positive experience is important to ensuring adherence. Having a good experience was described as being treated with respect, having friendly staff, the facility being clean and being seen on time. Other reported facilitators were financial assistance, flexible scheduling and reminders. They also reported that returning for appointments is facilitated by being in good health, meaning that they are more likely to return if they are not sick.

Recommendations for a Practice Change

The information obtained from this EBP project will be valuable in tailoring, client-centered approaches to follow-up care based on integrating best evidence with professional judgment and expertise and with client preferences. Given the evidence, women at MVHC frequently reported that transportation and financial barriers, fear, and negative experiences may impede their ability to return for follow-up appointments. A combination of interventions could be incorporated into the care of these patients.

Centralized Computerized Tracking System

Centralized computerized tracking systems could be utilized. MVHC is in the process of switching from paper charting to an electronic medical record which could possibly meet the needs of a centralized computerized tracking system. A follow-up coordinator who is a registered nurse would be responsible for using the tracking system to monitor the patients who need follow-up care. Utilizing this computerized tracking system would prompt the registered nurse to contact the patient via the phone for a one-on-one educational/counseling session.

Telephone Counseling/Education Session

An automated reminder phone call system is currently in place at MVHC but could be modified to include a one-on-one education/counseling session with patients. Evidence shows that interactive phone counseling sessions are instrumental in helping patients keep their appointments (Abercrombie, 2001; Eggleston, et al., 2007; Yabroff, Kerner, &Mandelblatt, 2000). This allows the nurse making the calls to assess the educational and emotional needs of the patients and to allow the patient to ask questions about the follow-up care. It also provides an opportunity for rescheduling the appointment if necessary that is convenient for the patient and also verifying the patient's current address and updating their contact information in the system.

Educational/Reminder Letter and Transportation/Financial Incentives

Following the telephone counseling session, an informational/reminder letter would be mailed to the patient explaining the importance of follow-up and reminding them of the appointment date and time. As determined during the counseling session, if transportation or financial barriers were identified as reasons for not returning, a transportation voucher (gas voucher or bus/cab pass) would be sent with the letter. The possibility of providing a financial voucher to those who are without insurance could be discussed with administration. The voucher would offset the required $25 co-pay and decrease the out-of-pocket expense to the patient.

An In-service Conducted by the Director of the Quality Committee

Women at MVHC also reported that a positive experience would help them keep their scheduled appointments. Based on the information collected, this meant that the environment was clean, the patient received good, friendly care, and they were treated with respect. An in-service conducted by the Director of the Quality Committee could be given to all employees including ancillary staff regarding the professional treatment and respect for patients and things that can be done to ensure that patients have a positive experience from the time of entry to time of discharge. Included would also be information regarding professionalism for those who talk to patients on the phone.

Next Steps

Having completed steps 0-4 of the EBP process, the next steps are to complete steps 5 and 6. First, a solid plan must be constructed in writing detailing each practice change and presented to administration. Upon approval of the plan, assigned staff will assist with the implementation process. Following the implementation process, Step 5- evaluation of each practice change would need to be done in order to ensure improvement in adherence rates. Collaboration with the Quality Committee could help to track the follow-up rates before and after intervention. Patient satisfaction could also be measured to evaluate whether these interventions have improved the patient's experience receiving care at MVHC. This is essential since a "good experience" was important to these women.

Step 6- dissemination of the outcomes of the EBP change would be completed. Dissemination can occur within the institution and its second location in Morgan co. It could also be valuable to disseminate the findings through public presentations and publications so that others in similar organizations can utilize and build on the body of knowledge found through this EBP project.

Conclusion

The death rate from cervical cancer should not be as high as it is, however, in order to decrease these numbers we must utilize the evidence to decrease barriers and increase facilitators to follow-up care after an abnormal Pap smear result. Determination of the most frequent barriers to patient follow-up within an agency incorporated with evidence from the literature can help with development, implementation and evaluation of these interventions.

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Appendix A

Table 1

Summary Table of Literature Regarding Barriers and Facilitators to Pap Smear Follow-up

Author, Year of Publication, and Title of Study	**Purpose, Sample, and Setting**	**Design**	**Findings**	**Limitations**
Level I				
Abercrombie (2001) Improving Adherence to Abnormal Pap Smear Follow-up	*Purpose:* To gain a better understanding of factors that affect follow-up and strategies found to improve follow-up	Systematic Review	Demographics, social support, lack of understanding, fear, inconvenient clinic hours, male providers, and insensitive staff affected follow-up. Telephone counseling, educational programs, and economic incentives improve follow-up.	Lack of generalizability due to small samples, descriptive study designs, and inadequate reporting of demographic information.
Eggleston, Coker, Prabhu, Cordray, & Luchok (2007) Understanding Barriers for Adherence to Follow-up Care for Abnormal Pap Tests	*Purpose:* To summarize the body of literature on adherence to follow-up after an abnormal Pap in order to develop interventions to decrease morbidity and mortality due to cervical cancer	Systematic Review	Lesion severity and health beliefs were consistently associated with adherence rates. Communication interventions, including telephone reminders, counseling and educational sessions increased adherence. Inconsistent evidence for associations among race, income, and age.	A range of "adherence" definitions makes comparisons across studies challenging. Studies with shorter time intervals may be prone to miscalculation

Author, Year of Publication, and Title of Study	**Purpose, Sample, and Setting**	**Design**	**Findings**	**Limitations**
Khanna & Phillips (2001) Adherence to Care Plan in Women with Abnormal Papanicolaou Smears: A Review of Barriers and Interventions	*Purpose:* Examine the extent of nonadherence, negative outcomes, barriers, and interventions for improved adherence to care	Systematic Review	Non adherence results from the interplay of emotional, logistic, cultural, or socioeconomic factors The most effective strategies to improve adherence are personalized reminders and case management dictated by size, style and structure of the practice.	Differences in researchers' definitions of non-adherence, study populations, and locations. Generalizability is limited.
McKee (1997) Improving the Follow-up of Patients with Abnormal Papanicolaou Smear Results	*Purpose:* Determine how to intervene to improve the quality of care *Sample:* 279 women with abnormal Pap smears *Setting:* Urban community health center	Systematic Review	Women not understanding results and younger women were less likely to return Barriers involving transportation, childcare, and insurance did not predict follow-up Socioeconomic status, education, language, or discipline were not associated with follow-up	A prospective assessment of rates of follow-up was not done after the interview limiting some conclusions of the data 19% of participants could not be reached Recall bias could have affected results

Author, Year of Publication, and Title of Study	Purpose, Sample, and Setting	Design	Findings	Limitations
Yabroff, Washington, Leader, Neilson, & Mandelblatt (2003) Is the Promise of Cancer-Screening Programs being Compromised? Quality of Follow-up Care after Abnormal Screening Results	*Purpose:* Integration of health behavior models at the provider and patient levels within a framework of realized access to care and application the model to a systematic review	Systematic Review	Provider communication, women with more serious findings, social support and coping styles, older women, being underinsured or, lower social class, financial constraints, monitoring of patients with abnormal results, and coordination of care influence follow-up care Race and ethnicity are not barriers scheduling difficulties, length of time at the office visit, unavailability of care when needed, and lack of confidence of the staff is associated with delayed follow-up care case management & interactive educational telephone counseling improved follow-up	

Author, Year of Publication, and Title of Study	Purpose, Sample, and Setting	Design	Findings	Limitations
Level II				
Eggleston, Coker, Luchok, & Meyer (2007) Adherence to Recommendations for Follow-up to Abnormal Pap Tests	*Purpose:* To evaluate whether timely adherence rates differ by race among women with abnormal Pap tests participating in a cost-free or reduced-cost program *Sample:* Women 47-64 years who received a referral for follow-up care after an abnormal Pap test 1999-2002. *Setting:* South Carolina	Phone interview	African American and non-Hispanic whites did not differ in follow-up adherence. White women with severe lesions were less likely to adhere in a timely manner. In African American women, rural residence was associated with decreased adherence. Less education was associated with increased adherence.	Low response rates Selection bias Use of aggregate data as indicators for individual socioeconomic status and rural residence
Engelstad, Stewart, Otero-Sabogal, Leun, Davis, & Pasick (2005) The Effectiveness of a Community Outreach Intervention to Improve Follow-up Among Underserves Women at Highest Risk for Cervical Cancer	*Purpose:* To evaluate the effectiveness of an outreach and counseling intervention at improving the rate of follow-up of abnormal Paps *Sample:* 348 women aged 18-74 years with abnormal Pap *Setting:* Alameda County Medical Center, Oakland, CA	Randomized Trial	The intervention produced significant increase in the rate of follow-up visits within 6 months. The intervention was equally effective when delivered to women in the control group who had no follow-up by 6 months.	Varying counseling foci Post-intervention study was not conducted

Author, Year of Publication, and Title of Study	Purpose, Sample, and Setting	Design	Findings	Limitations
Engelstad, Stewart, Nguyen, Bedeian, Rubin, Pasick & Hiatt (2001) Abnormal Pap Smear Follow-up in a High-Risk Population	*Purpose:* To evaluate the effectiveness of an aggressive follow-up strategy *Sample:* 108 Women 18-74 years old who visited the ED *Setting:* 300 bed, acute-care public teaching hospital in Oakland, California	Randomized control trial	65% of women in the intervention kept at least one follow-up appointment in 6 months compared with 41% of women in the control group Half the women in the intervention group vs. 19% in the control group had follow-up in 6 months and diagnostic resolution in 18 months.	
Marcus, Crane, Kaplan, Reading, Savage, Gunning, Bernstein, & Berek (1992) Improving Adherence to Screening Follow-up Among Women with Abnormal Pap Smears	*Purpose:* Design, implement, and evaluate three clinic-based interventions aimed at improving adherence behavior *Sample:* Over 2000 women *Setting:* 12 Los Angeles area primary health care clinics, most of which serve low-income patients of heterogeneous racial/ethnic backgrounds	Randomized trial	Significantly lower rates were found among clinics operated by the local health department, women with less severe Pap results, Black and Hispanic women, younger women, women with no health insurance and women with less than a high school education Transportation incentives and slide-tape program interventions has a significant positive impact on return rates	

Author, Year of Publication, and Title of Study	Purpose, Sample, and Setting	Design	Findings	Limitations
Marcus, Kaplan, Crane, Berek, Bernstein, Gunning, & McClatchey (1998) Reducing Loss to Follow-up among Women with Abnormal Pap Smears: Results from a Trial Testing Intensive Follow-up Protocol and Economic Incentives	*Purpose:* Evaluate the effectiveness of two interventions *Sample:* 1453 primarily Hispanic, *Setting:* 4 outpatient clinics at 2 major hospitals	Randomized control study	30% of the sample was lost to follow-up Patients assigned to the control group had a 36.1% loss to follow-up compared to 28.8% for the voucher condition and 29.0% for the intensive follow-up plus the voucher	

Author, Year of Publication, and Title of Study	Purpose, Sample, and Setting	Design	Findings	Limitations
Miller, Siejak, Schroeder, Lerman, Hernandez, & Helm (1997) Enhancing Adherence Following Abnormal Pap Smears among Low-Income Minority Women: A Preventive Telephone Counseling Strategy	*Purpose:* Test the effectiveness of a brief telephone counseling intervention directed to low-income, inner city women *Sample:* 828 women aged 14-54 years *Setting:* Colposcopy clinics in the Gynecologic Oncology Sections of the Departments of Obstetrics and Gynecology at Temple University Hospital or at the Allegheny University Hospital-East Fall campus both located in Philadelphia.	Randomized Trial Design	telephone counseling produced significantly higher adherence rates to the initial colposcopy visit compared with telephone confirmation. Standard care resulted in significantly lower adherence rates than telephone confirmation Those who responded with a positive Pap result with a particular psychological barrier may require more intensive and targeted counseling interventions.	identification of subgroups of patients most and least likely to benefit from these types of interventions

Author, Year of Publication, and Title of Study	Purpose, Sample, and Setting	Design	Findings	Limitations
Paskett, White, Carter, & Chu (1990) Improving Follow-up After an Abnormal Pap Smear: A Randomized Control Trial	*Purpose:* To test the efficiency of an intervention to increase follow-up compliance *Sample:* 161 women *Setting:* Women's Care Center, the obstetrics and gynecology clinic at the University of Washington Medical Center in Seattle	Randomized control trial	The compliance rate was 64.2% in the intervention (pamphlet group) and 51.3% in the comparison group	The study population contained fewer black women and fewer women with lower education than would be expected in national samples. The results of the study were only marginally significant from a statistical perspective
Level III				
Kaplan, Bastani, Belin, Marcus, Nasseri, & Hu (2000) Improving Follow-up after an Abnormal Pap Smear: Results from a Quasi-Experimental Intervention Study	*Purpose:* Assess the impact a computerized tracking protocol with transportation and financial incentives *Sample:* 4488 women *Setting:* 2 major hospitals, 2 comprehensive health centers, and 9 public health centers under the jurisdiction of the Los Angeles County Department of Health Services	Quasi-Experimental Intervention Study	Interventions were effective in increasing follow-up care among low-income women but they varied by level of care and year of implementation.	Intervention effects may have been underestimated Lack of statistical significance could be the result of outside events

Author, Year of Publication, and Title of Study	Purpose, Sample, and Setting	Design	Findings	Limitations
Level IV				
Cardin, Grimes, Jiang, Pomeroy, Harrell, & Cano (2001) Low-Income Minority Women at Risk for Cervical Cancer: A Process to Improve Adherence to Follow-up Recommendations	*Purpose:* Investigate the process and performance effectiveness of a centralized Pap follow-up protocol and identifying variables associated "lost to follow-up". *Sample:* 1,216 women with low grade SIL-lesions and women with high grade SIL lesions). *Setting:* Houston Department of Health and Human Services	Retrospective cohort study	Staff successfully notified 95.6% of women with low grade SIL and 97.9% of women with high grade SIL Overall, 84.2% of women scheduled appointments. African American women were 53% less likely to accept an appointment and 45% less likely to show up for an appointment than Hispanic or "other"	
Lindau, Basu, & Leitsch (2006) Health Literacy as a Predictor of Follow-up After an Abnormal Pap Smear	*Purpose:* To examine if literacy predicts patient adherence *Sample:* 68 English speaking women >18 years of age with abnormal Pap *Setting:* Chicago academic medical center	Prospective, continuity clinic-based study	Only 1/3 of the cohort adhered to follow-up recommendations. At 1 year 25% of the women had not return at all. Patients with inadequate literacy (assessed by REALM) were less likely to follow-up within 1 year. Patients perceived by their physicians to have low literacy were likely to fail to present for follow-up	Limited generalizability

Author, Year of Publication, and Title of Study	Purpose, Sample, and Setting	Design	Findings	Limitations
Melnikow, Benjamin, Chan, & Stewart, G. (1999) Do Follow-up Recommendations for Abnormal Papanicolaou Smears Influence Patient Adherence?	*Purpose:* To compare adherence to follow-up for colposcopy or repeated Pap *Sample:* A random sample of 225 women *Setting:* 3 northern California family planning clinics	Retrospective Cohort Study	Adherence to follow-up was low in the family planning clinics Adherence was improved with 3 reminders Women without insurance and women attending 2 out of 3 clinics were less likely to adhere to any follow-up recommendation	*Limitations:* Retrospective design, lack of randomization of women assigned to colposcopy referral vs repeat Pap smear A substantial number of medical records could not be located for review
Nelson, Greiger, & Mangione (2002) Effect of Health Beliefs on Delays in Care for Abnormal Cervical Cytology in a Multiethnic Population	*Purpose:* To determine if race and ethnicity, health beliefs, and cancer knowledge are associated with delays in care *Sample:* 733 women with an abnormal Pap *Setting:* Kaiser Permanente, Los Angeles Medical Center	Retrospective cohort study	Fatalistic health beliefs and misconceptions about cancer, but not race and ethnicity were independently associated with delays in care	Limited in the ability to make casual inferences about the effect of health beliefs and misconceptions about cancer on adherence behavior. There may be bias in the sample since the questionnaire was self-administered

Author, Year of Publication, and Title of Study	Purpose, Sample, and Setting	Design	Findings	Limitations
Level V				
Yabroff, Kerner, & Mandelblatt (2000) Effectiveness of Interventions to Improve Follow-up after Abnormal Cervical Cancer Screening	*Purpose:* To determine the effectiveness of interventions designed to improve follow-up after abnormal Pap smear	Qualitative meta-analysis	Cognitive interventions utilizing interactive telephone counseling were the most effective The single sociologic intervention, video- taped peer discussions was not associated with increased follow-up	Variability among patient populations category variability in the definition of the terms abnormal Pap smear, follow-up outcome measurement, and time frame
Level VI				
Coker, Eggleston, Meyer, Luchok, & Prabhu Das (2006) What Predicts Adherence to Follow-up recommendations for Abnormal Pap Tests Among Older Women	*Purpose:* To address the individual, provider, and environmental factors associated with Pap test adherence in a high-risk population *Sample:* 486 women aged 46-64 served by The National Breast and Cervical Cancer Early Detection Program (NBCCEDP) *Setting:* 2 southeastern states	Cross-sectional study Participation included completion of a 35-40 minute phone interview regarding a woman's abnormal Pap test experience.	Age was not associated with adherence African American women did not differ on their adherence to follow-up care Women with more severe lesions were more likely to adhere to follow-up recommendations Education level was not associated with adherence There was not a consistent pattern to suggest having child care or dependent adult care was associated with adherence	Low response rates

Author, Year of Publication, and Title of Study	Purpose, Sample, and Setting	Design	Findings	Limitations
Felix, Bronstein, Bursac, Stewart, Foushee, & Klapow (2009) Family Planning Provider Referral, Facilitation Behavior, and Patient Follow-up for Abnormal Pap Smears	*Purpose:* To determine family planning provider referral and facilitation practices *Sample:* All Medicaid-enrolled providers and women receiving family planning services *Setting:* Family planning clinics in Arkansas and Alabama	Survey	Private office-based physicians more likely to treat patients within their practice Private practice physicians were less likely to engage in referral facilitation 40% of those receiving care, reported receiving some care and a referral from their FP physician	Relied on FP providers' self-report of their referral and facilitation behavior 1/3 of clients reported physician referral behaviors they reported did not reflect actual referral practices Low response rate among public providers Low sample size
McKee, Lurio, Marantz, Burton & Mulvihill (1999) Barriers to Follow-up of Abnormal Papanicolaou Smears in an Urban Community Health Center	*Purpose:* To determine factors predictive of failure of women with abnormal Paps to return for colposcopy *Sample:* 279 women *Setting:* An urban community health center	Telephone survey	Women who did not know the results of their Pap or who incorrectly understood their results and younger women, were less likely to return for colposcopy. Socioeconomic status, education, primary language, health beliefs, fear of cancer, and clinician's gender or discipline were not associated with rate of follow-up. Barriers with transportation, childcare, and insurance did not predict follow-up	A range of 17 to 47 months from Pap smear to interview could have led to recall bias affecting results 19% of eligible participants could not be reached

Author, Year of Publication, and Title of Study	**Purpose, Sample, and Setting**	**Design**	**Findings**	**Limitations**
Percac-Lima, Aldrich, Gamba, Bearse, & Atlas (2010) Barriers to Follow-up of an Abnormal Pap Smear in Latina Women Referred for Colposcopy	*Purpose*: To identify patient-perceived barriers to follow-up after an abnormal Pap smear result among Latina women *Sample*: 40 Latina women Setting: Academic hospital affiliated with urban community health center	Qualitative, descriptive study	Anxiety/fear was the most common personal barrier Difficulties scheduling appointments and inadequate communication were the major system barriers.	Limited generalizability The study setting already has a program for the studied patients which may result in underestimating the challenges faced by women in settings without such efforts There may be bias in the interview process due to using two or more interviewers
Shireen (1998) Nonadherence to Follow-up Treatment of an Abnormal Pap Smear: A Case Study	*Purpose:* To highlight the role of illness explanatory models (individual's interpretation of illness) in nonadherence *Sample:* 32 year-old African American woman *Setting:* Metropolitan university family medicine clinic.	Case Study Qualitative data collected from by means of a semi-structured interview	Four broad themes emerged: (1) family explanation, (2) the nature of the cancer (3) mind-body connection, (4) faith in the higher power	Further in-depth study of the role these explanatory models of cancer play in non-adherence to treatment protocols is needed.

Author, Year of Publication, and Title of Study	Purpose, Sample, and Setting	Design	Findings	Limitations
Zapka, Puleo, Taplin, Goins, Yood, Mouchawar, Somkin, & Manos (2004). Processes of Care in Cervical and Breast Cancer Screening and Follow-up; The Importance of Communication	*Purpose:* To examine processes of care related to follow-up *Sample:* 1087 women 18 and older with an abnormal Pap *Setting:* Group Health Cooperative, Henry Ford Health Center, Kaiser Permanente Colorado, Kaiser Permanente Northern California	Surveys	Patients need clear messages about follow-up recommendations, 92% of patients with high grade lesions followed up vs. 80% of patients with low grade lesions that followed up	Sample size and response rates varied by plan. Generalizability is limited

Appendix B

Patient Questionnaire

Initials: _____	City of Residence_____		
Date of birth:_____ (month/day/year)	Race: (Choose all that apply) White African American Hispanic Asian Native American	Current relationship status: (Choose one) Single Married Divorced Separated Living together Widowed	Do you work outside the home? Yes No
If you work outside the home, how many hours do you work per week? _____ hours	Annual income: $0-5,000 $5,001-10,000 $10,001-20,000 $20,001-30,000 $30, 001-40,000 $40,001-50,000 Over $50,000	Medical insurance: Private Insurance Medicaid Medicare No Insurance	Number of living children? _____
Years of education: 0-5 6-8 9-12 1-2 years college 3-4 years college Greater than 4 years of college	Language primarily spoken at home: English Spanish Other _____	Primary location for women's health care: Muskingum Valley Health Center Private Dr. Office Family Health Services Other	Means of transportation: Personal vehicle Borrowed vehicle Bus Walk Other_____ _____
Reason for today's visit: Pap smear F/U for abnormal Pap Other _____	Last Pap smear: Within the past 6 months 1 year 2-3 years More than 3 years ago	History of abnormal Pap smear? Yes No	Did you follow up for your abnormal Pap smear? Yes No
List 3 reasons that prevent you from coming back for an appointment 1. 2. 3.			
List 3 things that could help you keep your appointment 1. 2. 3.			
Other comments?_____			

Appendix C

Staff Questionnaire

What is your role at the health center? Physician NP/PA RN LPN Medical Assistant Other_____
List 3 reasons that prevent patients from coming back for an appointment at the health center 1. 2. 3.
List 3 things that could help patients keep their appointment at the health center 1. 2. 3.
Other comments?_____

Appendix D

Table D1

Descriptive Characteristics of Patient Sample

	n	Minimum	Maximum	Mean	Std. Deviation
Age in years	49	18	66	35.6	11.54439
Hours worked outside the home	47	0	40	15.9	16.93187
Number of children	49	0	5	1.8	1.42887

Table D2

Characteristics of Patient Sample

	n	%
Race/ethnicity		
White	39	79.6
African American	5	10.2
More than 1 race	1	2.0
Relationship status		
Single	17	34.7
Married	14	28.6
Divorced	10	20.4
Separated	4	8.2
Living together	4	8.2
Work outside the home		
Yes	25	51.0
No	23	46.9
Income		
$0-5,000	10	20.4
$5,001-10,000	5	10.2
$10,001-20,000	12	24.5
$20,001-30,000	4	8.2
$30,001-40,000	3	6.1
$40,001-50,000	2	4.1
Over $50,000	1	2.0

Insurance		
Private	7	14.3
Medicaid	20	40.8
Medicare	2	4.1
No Insurance	18	36.7
Years of Education		
0-5	1	2.0
9-12	33	67.3
1-2 college	9	18.4
3-4 college	4	8.2
Greater than 4 college	2	4.1
Language		
English	49	100.0
Primary Location for health care		
MVHC	45	91.8
Private office	1	2.0
Family health services	3	6.1
Transportation		
Personal vehicle	42	85.7
Borrowed vehicle	3	6.1
Other	3	6.1
Reason for visit		
Pap smear	32	65.3
Follow-up abnormal Pap	1	2.0
Other	12	24.5
Last Pap smear		
Within 6 months	12	24.5
1 year	21	42.9
2-3 years	11	22.4
More than 3 years	4	8.2
Never	1	2.0
History of abnormal Pap smear		
Yes	21	42.9
No	26	53.1
N/A	1	2.0
Did you follow-up for abnormal Pap		
Yes		
No	20	40.8
N/A	3	6.1
	26	53.1

Appendix E

Table E1

Patient Responses to Things that Prevent them for Returning for Follow-up

Category	n	%
Transportation/distance to travel	12	15.0
Financial	11	13.8
Negative experiences	11	13.8
Other commitments	10	12.5
Child or family care	7	8.8
Fear	6	7.5
Ill/physical condition	6	7.5
Appointment time or length	4	5.0
Keeps appointments	4	5.0
Weather	3	3.8
Uncodable response	3	3.8
Forgot	2	2.5
No need for appointment	1	1.3

Table E2

Patient Responses to Things that Help them Keep Follow-up Appointments

Category	n	%
Positive experience	12	23.1
Motivated by health	7	13.5
Financial assistance	6	11.5
Flexible scheduling	6	11.5
Keeps appointments	6	11.5
Reminders	5	9.6
Transportation assistance	4	7.7
Not amendable to assistance	2	3.8
Appointment time/length	1	1.9
Assistance with fear	1	1.9
Uncodable response	1	1.9

Appendix F

Table F1

Staff Responses to Things that Prevent Patients from Returning for Follow-up

Category	n	%
Transportation	6	26.1
Health literacy issues	4	17.4
Financial	3	13.0
Childcare	2	8.7
System navigation issues	2	8.7
Unwillingness or lack of motivation to adhere	2	8.7
Illness	1	4.3
Weather	1	4.3
Resolution of the problem	1	4.3
Forgot appointment	1	4.3

Table F2

Staff Responses to Things that Help Patients Keep their Appointments

Category	n	%
Transportation assistance	5	25.0
Reminders	4	20.0
Improving health literacy	3	15.0
Improving system knowledge	2	10.0
Provide childcare	2	10.0
Financial assistance	1	5.0
Incentives for visits	1	5.0
Navigation services	1	5.0
Flexible scheduling	1	5.0